

First Words

A First Steps Communications Tool for Families From Family to Family

ALTERNATIVE vs. CONVENTIONAL TREATMENTS

“...alternative treatments can be a source of disagreement between physicians and families.”

Alphabet Soup

Each month we will cover a few abbreviations or acronyms parents might hear or see while in First Steps. Sometimes it is awkward for families to ask. Do you know these?

- AIT = Auditory Integration Training

A therapeutic technique designed to help people with auditory processing problems.

- TES = Therapeutic Electrical Stimulation

A type of electrical stimulation used in conjunction with physical or occupational therapy to strengthen muscle and improve functional abilities.

As parents of children with disabilities or delays, we constantly seek treatments that may help improve the quality of life for our children. Many times, when conventional treatments (including surgery and prescription medication) don't seem to be offering much hope to us, we turn to "alternatives". The list of alternative treatments is long and growing all the time. Alternative treatments can include (and this is just a short list) acupuncture, chiropractic intervention, cranial-sacral therapy, massage therapy, vision therapy, reflexology, vitamin therapy, conductive education, auditory integration therapy and magnetic therapy. It's difficult to find a precise definition for alternative therapies, but the consensus is that it's "those measures whose aim is to prevent, diagnose and improve disease or disability, but which have not been approved by health authorities and/or do not have scientific research behind them."

Parents/families often consider alternative treatments out of frustration. We don't feel like conventional treatment is effective, or at least has had disappointing results. We want the best for our child and will try whatever seems reasonable to us, leaving no stone unturned. We may wish to have more control over our child's fate, and believe that this is best done by taking charge of our child's treatment and making our own decisions. In addition, alternative treatments sometimes offer hope of improvement that exceeds that of conventional treatment.

However, when we, as families, go to our medical doctors for help and information about alternative therapies/treatments, we are sometimes met with criticism and negative opinions. Medical professionals are scientists and typically endorse what can be proven scientifically. Sometimes, the physician may believe that an alternative treatment may actually cause harm, or that a family will invest (literally) a great deal into a treatment, only to be disappointed with the result. Perhaps medical professionals feel a direct challenge...."what if it works," or maybe don't have enough information to endorse an alternative treatment. Whatever the reason, alternative treatments can be a source of disagreement between physicians and families.

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ALTERNATIVE vs. CONVENTIONAL TREATMENTS

How then, do we decide what is best for our child? Several factors should be considered. First, and most importantly, does an alternative therapy have risks? Could you jeopardize the progress your child has already made? Next, cost will most likely be an issue. Alternative therapies are generally not covered by private insurance or government health care, although some are being recognized more and more. Be sure to check into what might be covered and what costs you will be responsible for. Gather as much information as possible. Talk with those that will administer the treatment, talk with other families who have used the treatment, talk with your physician (he/she may not agree, but he/she may also be able to give you resources or places to look for more information) and read as much about the treatment as possible. Finally, remember therapies or treatments that are successful for one child may not be successful for yours, and vice versa. Everyone is different and nothing works for all.

Advocacy Tip of the Month

In past columns we have talked about organization being one of the keys to advocacy. Here are some tips from parents that you may find helpful:

- ◆ *Organize information about your child in one binder if possible, so you have it all at your fingertips whether you are going to the hospital, having an IFSP meeting, meeting a new specialist, etc. If you have too much information for one binder, divide it into specific topical binders, such as medical info, First Steps, schools, insurance, etc.*
- ◆ *Use photo album pages in your binder, or the various organizer pages available at office supply stores that have pockets in them. In these pages you can keep business cards for physicians, service providers, school contacts, and others you consult about your child. This reduces frustration and digging for information we often need to look up ourselves or provide to others.*
- ◆ *Keep a log of medical tests/procedures your child has completed. Include date, physician, place where the test was done, and results. This will help you with accurate reporting later and will help avoid duplication of services and tests.*
- ◆ *Take your binder with you to any appointment or meeting you have about your child so everything you might need is right at your fingertips!*

RESOURCE AVAILABLE FROM NBC

Recently, NBC featured a week-long series called “Autism: The Hidden Epidemic?” The series featured several hours of footage about many aspects of autism including the importance of early detection, causes of the disorder, treatment plans, educational programs, and vocational training. Other features include Michael Marino’s story (son of football star, Dan Marino) and an interview with actor Anthony Edwards (formerly of ER), who is an honorary board member of Cure Autism Now. NBC has made available a DVD which contains all of the series programming. To receive a copy of the DVD, visit their website at <http://www.autismspeaks.org>. The DVD is available for a \$4.96, which includes the cost of shipping and handling.

Resources for Families and Providers

Check out these sites where you can learn more about organization and advocacy from parents:

Special Child

<http://www.specialchild.com/tips.html>

Family Voices

<http://www.familyvoices.org>

Special Needs Family Fun

<http://specialneedsfamilyfun.com>

Ideal Lives

<http://www.ideallives.com/articles.php>

Bridges for Kids

<http://www.bridges4kids.org>